PCAST Report Workgroup
<mark>Draft Transcript</mark>
February 10, 2011

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director
Good morning, everybody and welcome to the HIT Policy Committee's PCAST Work Group. This is a Federal Advisory Committee, so there will be opportunity at the end of the call for the public to make comments. Just a reminder for workgroup members to please identify yourselves when speaking.

Let me do a quick roll call of the membership.

Paul Egerman – Software Entrepreneur
Here.

William Stead – Vanderbilt – Chief Strategy and Information Officer
Here

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Here

Hunt Blair – OVHA – Deputy Director
Here

Tim Elwell – Misys Open Source Solutions – Vice President
Here

Carl Gunter – University of Illinois – Professor
Here

John Halamka – Harvard Medical School – Chief Information Officer
Here

Leslie Harris – Center for Democracy & Technology – President & CEO
Here

Stan Huff – Intermountain Healthcare – Chief Medical Informatics Officer
Here

Robert Kahn – Corporation for National Research Initiatives – President & CEO

Gary Marchionini – University of North Carolina – Dean & Professor
Here

Steve Undra
Here

Jonathan Perlin – Hospital Corporation of America – CMO & President
Here

Richard Platt – Harvard Medical School – Professor & Chair

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Here

Mark Rothstein – University of Louisville – Chair of Law and Medicine
Here

Steven Stack – St. Joseph Hospital East – Chair, ER Dept

Eileen Twiggs – Planned Parenthood Federation of America – Director
Here

Chuck Friedman – ONC – Deputy National Coordinator
Here

Jodi Daniel – ONC – Director Office of Policy & Research
Here

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability

Joy Pritts – ONC – Chief Privacy Officer

Judy Sparrow – Office of the National Coordinator – Executive Director
Did I leave anyone off? Okay, with that I'll turn it over to Paul Egerman.

Paul Egerman – Software Entrepreneur
Great, good afternoon or good morning, this is our conference call for the PCAST Report Workgroup. I very much appreciate everybody's participation. This is a public call and so there will be time at the end of the call for members of the public to make their comments and those comments are very much appreciated, and so I would like to thank any members of the public who are listening in on our call because we really want to hear your feedback. What we are trying to accomplish today is to do an additional information gathering leading up to our February 15th and 16th hearing. We just did a roll call, here is a list of the members of this workgroup, which we are very proud to have such a strong group of diverse membership and it's similar for almost all the ONC workgroups, we have a great workgroup team.

This is our workgroup charge, to make sure everybody remembers, the PCAST report is a reference to a report published by another advisory committee that … presence council of advisors in science and technology that was published on December 8th and this workgroup is charged to the task of assisting ONC in synthesizing and analyzing the proper comments and we are also discussing implications of the report and its recommendations to ONC on current ONC strategies. We're assessing the feasibility and impact of the PCAST report on programs and we are going to elaborate on how those recommendations can be interpreted into this strategic framework.

This is a schedule of our meeting dates. We are intending to complete our work by April 13th in order to produce a report that we will be producing for the HIT policy committee. We have a conference call today; February 15th and 16th, is our hearing in Washington D.C. and then we have two calls after that. The hearing becomes what I would call like a pivot point in our discussions. Up till now and up through February 15th we are really gathering information and listening, making sure that we understand the report, understand peoples feedback about the report, but starting February 16th is the time when we're going to be rolling up our sleeves and trying to apply whatever information we've learned about the PCAST report and from comments from various stakeholders to making sure that we can think about what comments we want to make in our report in April.

That's the basic schedule. We are going to start today with a discussion from Chuck Friedman who is the Chief Science Officer of ONC. Before I do that, let me ask my colleague Bill Stead, do you have any comments? Anything that you would like to add?

William Stead – Vanderbilt – Chief Strategy and Information Officer
No, we're on track.

Paul Egerman – Software Entrepreneur
That's great. What we're going to do today is, first we're going to hear from Chuck Friedman then we're going to do a review of documents that we had sent out a little bit earlier that essentially got slightly modified to try to make sure that we have some sense of a agreement about at least at a high-level what are the basic directions that have been set in the PCAST report and then after that to the extent we have time we'll talk a little bit more about how we're going to organize ourselves around the hearing.

That's our agenda and I think the first part of it - the next part is Dr. Friedman.

Chuck Friedman – ONC – Deputy National Coordinator
Thank you, Paul. Should I just begin?

Paul Egerman – Software Entrepreneur
You should begin.

Chuck Friedman – ONC – Deputy National Coordinator
Okay, thank you and good afternoon, good morning, everyone. I'm going to be presenting about a workshop that ONC hosted entitled Next Generation Interoperability for Health.

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This workshop was held January 20th and 21st and is actually one of a set of workshops that my office within ONC, the office of the chief scientist, has held on occasion as one-time only multi-stakeholder gatherings to contemplate the future. To scan the horizon and as best a gathered group of experts can create a vision of what might be coming and what might be the best way to capitalize on what might be coming and incorporate it into our plans.

In this case we put together a workshop whose purposes you see on the slide was to explore how new and emerging technologies can establish more efficient, trusted, secure, skillable, and sustainable mechanisms for health information exchange. I think we've got all the right words in there. We had 55 attendees representing academia, non-profit organizations, the private sector, and the federal government. This workshop clearly relates, as will become I think even clearer later, to the PCAST workgroups charge.

I do want to point out that the net-cast by this workshop was wider than the PCAST report and in fact the workshop was conceived at a time when we knew that the PCAST report was forthcoming, but really did not know what it was going to say.

Let me say one more thing before moving on to the next slide. What I'm going to do today is actually not present many of the specifics of the results of the workshop because we are still working on generating those, but I'm going to describe what happened at the workshop. Give you a sense for what the findings are going to be and then at the end I'm going to ask you all to tell me given that the workshop focused to a significant extent on the PCAST report, but also a wider set of issues, how we might over the next couple of weeks be helpful to you in addressing some specific questions you might have that can be eliminated by the proceedings and the findings that came out of this event.

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This workshop was an amalgam of a number of perspectives that were formally considered in the sense that they were structured in and presented and discussed. We brought in two, what might be called, technological perspectives. One is the perspective of ultra large scale systems that may not be familiar to all of you and that I will speak about in a bit more detail in a moment. Another that probably is familiar to you and clearly relevant to the topic at hand is the concept and the technology being developed around the concept of the Semantic Web.

We also folded in several recent reports, primarily the PCAST report that is the focus of your work, but also at least one report out of the Institute of Medicine their recent report on the digital infrastructure for our learning health system.

We also had several of our SHARP research sites including the one that your colleague Carl Gunter directs represented in the group and through their presence folded in their research agenda's.

Paul Egerman – Software Entrepreneur
Chuck, could you just take a minute and explain what SHARP is in case some of the people -

Chuck Friedman – ONC – Deputy National Coordinator
Oh, thank you, please stop me anytime any kind of clarification might guide as necessary. SHARP stands for, as shown on the slide, Strategic Health-IT Advanced Research Products. SHARP is a family of four research grants that ONC funded as part of the high-tech initiative. There are SHARP projects based at Boston Children's focusing on innovative platforms for health IT systems. Carl Gunter's center at Illinois focused on security. Chris Shoots center at Mayo focused on secondary use and … Center at the University of Texas, Houston focused on cognitive decision support issues.

Next slide please.

We invited a range of attendee's; we mentioned in a previous slide from once they came, this is the set of competencies or experiences that created the structure for the assembly of the group. We had folks from Advanced Computer Networks and Communications, we had folks knowledgeable about the somatic web, learning healthcare systems, and automated support of population health, cloud computing. We had folks knowledgeable about privacy policy and standards. We had a number of federal agencies represented, as I mentioned the SHARP grantees, we had several of the original authors of the Department of Defense and Carnegie Mellon over a large scale system report and we had three of the principals of the PCAST study there as well.

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Paul Egerman – Software Entrepreneur
Were any providers there?

W
That was my question.

Chuck Friedman – ONC – Deputy National Coordinator
No, except to the extent that some of the folks were also providers.

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Just a word about the extra-large scale systems perspective, because it may not be as familiar to you as the other conceptual frameworks that fed in to the conference, this is actually best expressed, and was first expressed in a report published by the Carnegie Mellon Software Engineering Institute I believe in 2006, and you have a link to the page there which in turn gives you a link to their full report. We have found this perspective very helpful because it seems to align with the scale and the complexity of what

the nation is trying to do to build a nationwide health information network to support healthcare and population health.

One of the important insights that derived from this report is that it frames these kinds of undertakings as engineering projects and brings in concepts from engineering and shows how they apply. Some of those concepts include and I've only listed a few of them here that apply specifically to these very, very large systems as requirements for them to function include: decentralized control, these systems are so large and diverse you can't control them from a central point; the diversity and evolution and sometimes conflicting nature of the requirements on these systems; the importance of minimizing standardization up-front, the need to just get a few standards right and allow the many stakeholders that participate in these systems to innovate around them. I think we saw this principle best illustrated in the evolution of the internet itself that ultra-large scale systems continuously evolve and must be viewed as never static. An important feature is that they are socio-technical systems and the users, the people involved and their culture and their sociology must be seen as part of the system.

Finally, in this list, and it's not a complete list, the notion that in anything this complicated no matter how well-designed and conceived it is failures are inevitable and the system must be designed to tolerate a certain level of failure. That's not even ULS-101, that's sort of skimming the surface, but I hope I whet your palate a little bit around this idea and hope that you might drill a little bit more deeply into it.

Paul Egerman – Software Entrepreneur
Is the thought process of you in National Health Information System as an ultra-large fail system?

Chuck Friedman – ONC – Deputy National Coordinator
I'm sorry, I didn't hear the whole question, could you repeat it please?

Paul Egerman – Software Entrepreneur
In the thought process, I'm looking at your second bullet and your third bullet, are you looking at the National Health Information System as an ultra-large system?

 Chuck Friedman – ONC – Deputy National Coordinator
Precisely, and in that component of this workshop that's exactly what the folks that come out of this ULS perspective try to do, to connect what we're doing and what we need to do on a national scale with the framework and the requirements that an ultra-large scale system must meet.

William Stead – Vanderbilt – Chief Strategy and Information Officer
Could I just clarify one thing?

Chuck Friedman – ONC – Deputy National Coordinator
Sure.

William Stead – Vanderbilt – Chief Strategy and Information Officer
I think it would actually be the healthcare system that's being looked as an ultra-large scale system and therefore the information infrastructure might need to reflect that. I think it's actually the healthcare system itself that's behaving like an ultra-large system. Maybe, I have that wrong.

Chuck Friedman – ONC – Deputy National Coordinator
That wasn't the way we were viewing it in the context of this workshop. There was a focus on information and the challenges of national interoperability as itself being a complex system. I also think, Bill, and your point is very well taken that another feature of ultra-large scale systems is their hierarchical nature and there are systems within systems. Maybe, the national health system as an ultra-large scale system is itself a subcomponent of an even larger system.

William Stead – Vanderbilt – Chief Strategy and Information Officer
Thank you.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Hi Chuck, this is Wes Rishel

Chuck Friedman – ONC – Deputy National Coordinator
Wes was there.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I also blogged about this the other day. It was very mind opening presentation for someone who wasn't familiar with it, but to my mind it mostly stated the problem rather than getting at solutions and then in the second day one of the speakers made a few off-hand comments that started to sound like solutions or elements of the discipline of ultra-large systems, something like that. Is there some way to find and distribute to our public here some things that get more to how it works as opposed to stating what the problem is? I think that would be very helpful to everyone.

Chuck Friedman – ONC – Deputy National Coordinator
Yes, great comment, Wes, and actually you anticipated something that comes along a few slides from now when we talk about the products at the conference. There was only so much we could do in a day and three-quarters, so what we've actually asked for and are now getting to compensate somewhat for those limitations is a further exigencies on some of these issues and in particular we have asked the person in question who made those important points toward the end of the workshop to give us a much longer and much more elaborated vision of that and he's working on that.

I'll show where that fits in to the whole reporting process in a second, but thanks for bring that up, Wes.

Could we move on to the next slide?

This is where this point comes up. This is how the workshop unfolded over two days and post-workshop. On the first day we had a series of presentations with very, very rich and intense discussions, first on ONC's initiatives, then on the PCAST report, then on the ultra-large scale systems perspective, and then on the somatic web.

On the second day we broke the participants up in to four groups. We expressed four principles or high-level requirements that a national system of information mobility and liquidity would have to satisfy. Hopefully, we did these and I'll show them to you in a minute in a sufficiently general way that did not pre-constrain the problem and force certain solutions to the top.

We then asked each breakout group to address one of these principles but to do it in the context of the other three and we asked them to develop short, medium, and long-term plans folding in explicitly the perspectives introduced on the previous day to achieve the requirement that they were charged to explore.

Then as I was saying in response to Wes's comment, we recognized in several ways there were things undone by the time we formally closed the workshop, so we have asked several people to conduct further analysis of the results of the group and we've asked for further briefings on special topics. We've asked for one specifically on lessons learned from the internet. We've asked for one on how the somatic web applies, in more detail. We also asked for one on the ultra-large scale system perspective.

Those will be part of the final report when all is said and done.

Next slide please.

Here are the four high-level principles, you can call them high-level general requirements that we charged the group with. Number one is the information follows the patient principle that is familiar to all of us. Number two brings in the importance of decision support based on this assembled information and then reflecting most up-to-date knowledge. Number three brings in learning and quality improvement and

policy formulation. In other words, how this would support a learning health system. Number four goes to the issue of patients having access to their own information.

I didn't correct the slide because this was actually as we presented it to the participants, but several folks at the workshop said we shouldn't use the word patient in this conceptualization because it connotes a focus on illness rather than health. I didn't correct it here, but we take that point very seriously.

Leslie Harris – Center for Democracy & Technology – President & CEO
I guess I'm pretty stunned to see point four is partly about access, it also has this highly granular choice about it's shared, which is a misperception about what privacy is and it's starting to show up - it showed up in the PCAST report and I certainly was hoping that privacy would not get reduced in anything that's happening in HHS. How did that get here? It's a very controversial and backward looking concept on what constitutes privacy and I'm very disturbed to see it reflected again here.

Chuck Friedman – ONC – Deputy National Coordinator
Leslie, I'd love to have a separate conversation with you about that and to understand probably in greater depth than we have time to achieve here.

Leslie Harris – Center for Democracy & Technology – President & CEO
Right, I'm just trying to understand why it keeps coming up. It's obviously an engineer's idea of what privacy is, but I'm very, very worried that it would be in a report here.

Chuck Friedman – ONC – Deputy National Coordinator
Could I ask and not to reverse the question but, how would you rephrase number four?

Leslie Harris – Center for Democracy & Technology – President & CEO
Well, I cannot do it right now, but privacy is a much more complicated question than patient consent and the requirements would be substantially different because you're worried about security, you're worried about sharing, I can give you our comments on privacy for PCAST and I think it would probably answer your question.

Chuck Friedman – ONC – Deputy National Coordinator
Thank you, we really appreciate that.

Leslie Harris – Center for Democracy & Technology – President & CEO
I think the … comments will also cover that in some detail.

Chuck Friedman – ONC – Deputy National Coordinator
Yes, thank you that would be very helpful. I will tell you that your concern did not come up at the workshop. There were people who are immersed deeply in privacy issues there, but we'd be delighted for your input.

Mark Rothstein – University of Louisville – Chair of Law and Medicine
I want to second Leslie's comment.

Leslie Harris – Center for Democracy & Technology – President & CEO
Thank you.

Chuck Friedman – ONC – Deputy National Coordinator
Thank you, very helpful, appreciate it.

Mark Rothstein – University of Louisville – Chair of Law and Medicine
I think some of these points of view were represented that I believe Devin McGraw headed that session.

Leslie Harris – Center for Democracy & Technology – President & CEO
I know what our position is and her position is for - I am completely confident this wasn't her formulation.

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She was asked to lead a group that responded the statements and so.

Leslie Harris – Center for Democracy & Technology – President & CEO
Responded to it, yeah, ok.

Paul Egerman – Software Entrepreneur
I just wanted to ask the participants to say your name before you talk. In deference to the public who may be listening and may not be familiar with the voices.

Chuck Friedman – ONC – Deputy National Coordinator
It may be Leslie that the work that was done by the groups, and I believe Deven did share with the group that it's … principal for takes the solution in a direction that when reflected back casts the original problem in a different light and maybe corrects it.

Leslie Harris – Center for Democracy & Technology – President & CEO
Okay.

Chuck Friedman – ONC – Deputy National Coordinator
That's another possibility.

Leslie Harris – Center for Democracy & Technology – President & CEO
Okay, thank you, I get it.

Chuck Friedman – ONC – Deputy National Coordinator
Move on to the next slide.

Paul Egerman – Software Entrepreneur
Before you move on Chuck, I actually have one minor comment too about your point number four. I was interested that it said highly granular choice, what's the difference between highly granular and granular choice?

Chuck Friedman – ONC – Deputy National Coordinator
We thought it was a different kind of problem if the choice was everything flows or everything doesn't as opposed to having some greater level of control. That greater level of control beyond, turn it all on or turn it all off, is what we meant by highly granular.

Paul Egerman – Software Entrepreneur
Okay.

Leslie Harris – Center for Democracy & Technology – President & CEO
Okay.

Paul Egerman – Software Entrepreneur
Thank you.

Chuck Friedman – ONC – Deputy National Coordinator
Okay, move on to the next slide please.

Just a preview when we are ready and we're getting there to present the actual findings this is a form that they may take. It actually reflects what the groups produced and these are a list of things that must be accomplished to address each of the four principles/requirements put in to three time buckets; things that must be done in the next one or two years, in the next three to five years, and then the next five to ten

years. We just wanted to give you a sense of what resulted from the groups and what will be certainly one of the ways, almost certainly not the only way that we report the results of the workshop.

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This brings me to a conclusion and the conclusion is really a question for you and I'm going to take out my pen and I'm going to write what you all say, how can we help you? I put down some ideas; number one there was a lively discussion that followed the PCAST presentation. On day one we had Chris Castle of Bill Press and Craig Mundy there and we have a verbatim transcript of the discussion and could do a content analysis of that discussion if that would help you. We would benefit in doing that content analysis from knowing what would be the guiding questions on your minds that might give focus to that content analysis.

Second, we could provide for you an overview of the entire vision that emerged from the workshop and we could do this focusing, since the PCAST report is your primary focus, on how and where the PCAST recommendations were folded in. I will give you a preview and Wes and Carl who were there can, I think endorse this, but if you don't agree with me please say so, that in general the PCAST vision of "atomic" data elements with Rich Betadater was endorsed and was incorporated into the plans in those 12 cells that I illustrated in the previous slide. I just can say at a very, very high and general level that the participants as a group did endorse the PCAST vision. They had lots of discuss about certain aspects of it which going to question one on the slide we could summarize for you if you would like to request that from us.

Then, number three on the slide, are there any other ideas that you have for ways we could be helpful? That concludes my presentation. I guess I would appreciate some discussion of what is on the last slide.

Paul Egerman – Software Entrepreneur
Great.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I would sort of adjust your summary just a little bit from my recollection. I would say that we were not asked to endorse or not endorse the PCAST report per se, and that we did and didn't whatever that is that we discussed means of achieving elements of the PCAST report and structures under which some of the elements of the PCAST report were resonant with the items on your 12 item grid there. I would fall short of saying we endorsed the principles of the PCAST report, just because we were specifically asked not to consider that question.

Chuck Friedman – ONC – Deputy National Coordinator
That's fair Wes and I guess what I did was take a leap of inference from the presence of many of the principles advanced by the PCAST report in those 12 squares as an implied endorsement, but I think your restatement is a fair one that I should be attentive to that you were not asked for an endorsement and therefore in any direct sense nor was one given.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yeah, and I think everyone can find things they agree with in the report and that's particularly true when there is no specific timeframe associated with agreement. It's a lot harder, takes more serious thought and discussion to take the … report and put them in to specific timeframes and agree to them.

Gary Marchionini – University of North Carolina – Dean & Professor
I had kind of two concerns that have been sort of nagging me right from the start. One has to do with people's willingness to adopt, especially patient's privacy settings and maintain that. I think that's been expressed in previous meetings, so I'm going to just put that on the table. Going to the other one that relates to the slide and that's this atomic data element, that really needs to be defined. In the internet the reason things go to work is that there were atomic elements like a webpage that got defined as the landing place for, let's say a link, and you couldn't go into a sub-set of a webpage at least in the early

implementations. Has there been much discussion about what these atomic elements would be? Is that a medical event? Is it something within a visit to a physician or to a hospital or a treatment that takes place over perhaps a very long time? It'd be very helpful to me to understand more about what the thinking is about these atomic - how atomic is it - down to the individual character in a record.

Chuck Friedman – ONC – Deputy National Coordinator
It's a great point. If you're asking me was it discussed at the meeting, I'm virtually certain it was. If you are asking is it an important topic, of course it is, it comes up just about every place where I am, where this report is discussed. One of the metaphors is are we talking about protons, atoms, or molecules? How big is an atom? I think rather than trying to remember on the fly now what was discussed about this, I'd like to write that down as something that we should include in our refined product that we deliver to you.

Gary Marchionini – University of North Carolina – Dean & Professor
That would help me for sure. Thank you.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
My question was almost identical to what Gary's, but I would like since you are writing it down specifically in this slide where you go, they endorse, I'd like to know at what level of … they endorse atomic data on?

Chuck Friedman – ONC – Deputy National Coordinator
Okay, I think combining Dixie you comment with Wes's I think one lens through which we might view the proceedings is to the extent that anything was endorsed, what was endorsed and what context was it endorsed? In particular, if there were concerns about specific aspects of the report that could lead to a conclusion that perhaps those weren't endorsed by the group, what were those? Is that a fair extension of your question?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes, thank you.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
A lot of these issues particularly about the atomicity and even about the fundamental premise that a physician treating a patient wanted to access to all this information were I think taken up in the questions and answers from the principles with the principles of PCAST report to the extent you can cover their presentations and the Q&A sessions in some kind of a summary. I found that section to be very enlightening in terms of avoiding different people reading into the language of the PCAST report, different interpretations. In some ways, it's almost like a poem in the sense that, if you want to like something or you want to dislike something you can find it in the language there, whether another person does or not.

Chuck Friedman – ONC – Deputy National Coordinator
Let me just be sure I understood what you were saying as it translates in to something we might do, I think you're saying that in some cases elements of the report that were poetic in nature and could be seen as things to like or things not to like depending on your predisposition were specified or clarified through the discussion to be a little more clear as to what the committee really meant and to the extent that happened we should call it out, is that the -

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I would think if you're able to do a summary of what was presented, perhaps with the slides and a summary of the questions and answers, an outcome of that activity would be for people to have a little more grounding in what the author's had in mind as they talk about it. I don't think you need to get in to evaluating the surprise value. I would say that the discussions on what was their evidentiary base for reaching some conclusions that came up in the questions and answers were very helpful.

Chuck Friedman – ONC – Deputy National Coordinator
Thank you.

Stan Huff – Intermountain Healthcare – Chief Medical Informatics Officer
One comment, I'd be interested if there was further expansion at the conference about the, I'm forgetting the exact wording, about ultra-large scale systems, but the minimization of standards and I wonder how that was applied and exactly what it means. I guess the concern is whether we have the same assumptions about what we're trying to accomplish with sharing the medical data versus say the typical internet scenario. The difference being that the premise of the internet right now at least is you query, you get back things, you've got a human filter that decides what's valid and what's not valid and the person makes a decision about whether to rent a car or what the best choice is. I think we're shooting, at least in my mind, for a higher target of interoperability between systems, not necessarily always filtered by a human. I'm concerned that comment, for instance, would be interpreted to say, well, we really don't need to worry about using standard terminologies or we really don't need to worry about the structure of data that in fact may be needed to automate a lot of the behaviors that we're trying to achieve in the healthcare system, especially advanced decisions support kinds of applications.

Chuck Friedman – ONC – Deputy National Coordinator
Stan, that's an important point in and of its self, let me generalize it. How helpful would it be to the workgroup for us to shine some light on the ULS and somatic web components of the meeting that actually went beyond the PCAST report per se. I ask that for a lot of reasons including the fact that Stan's statement took me to the somatic web, because one of the purposes of the somatic web is to enable a lot of things to happen on the web that right now require human intervention to happen automatically.

Stan Huff – Intermountain Healthcare – Chief Medical Informatics Officer
That would be very helpful to me.

Paul Egerman – Software Entrepreneur
I agree, it would be helpful, although, sort of picking up on Wes's comment about poetry, we can all read these things and interpret them however we choose. When I thought minimization of standards my interpretations was, that was like the technical standard of how you communicated the information and what the syntax was, but that's not necessarily any reduction in what we call in healthcare like vocabularies. In order to do decision support you need to have some definitions. I … interpret minimization of standards meaning necessarily that was any different. That was inconsistent to what is currently going on.

I don't't' know, I just got it right or wrong.

Carl Gunter – University of Illinois – Professor
Could I speak? I was at the meeting I think we were told we were not suppose to reach … recommendation about the report … very strict in terms of these sorts of things. It was extremely useful for maturing the discussion of the … techniques available to address it and I'll just make some brief comments on those.

Chuck Friedman – ONC – Deputy National Coordinator
Carl, I'm having trouble hearing you.

Carl Gunter – University of Illinois – Professor
Let me see, can you hear me any better now?

Chuck Friedman – ONC – Deputy National Coordinator
Yes.

Carl Gunter – University of Illinois – Professor
There was lively discussion of the question of the atomic data element, looking at the question of what kind of context might be lost if flattening were done so that the data became atomic and I think that it was

beginning to mature the discussion of what exactly we're talking about here and it illustrates how far we have to go in understanding quite specifically what we're dealing with, with this. Same thing for the technologies the ULS discussion and somatic web - we weren't allowed to reach consensus. I can at least say what I thought which was that the ULS system is an articulation of the problems of a weakly regulated cyber infrastructure. You have a list of things, and it doesn't really matter if it's large or small, if it's weakly regulated it's going to have these kinds of problems. There's the question as, is that the system we want to have for this and if it is what kind of solutions might we have for some those problems? Like particularly, the kinds of failures and a lack of stakeholder agreement that you would see.

Then for the somatic web there are things like it's technology that will help you with some of interoperability problems we'll face that may help to solve some of these problems to do with what standard depicts, so you might be able to have very refined standards and very not very refined standards living side-by-side and be able to deal with that.

The overall meeting was I think helpful in maturing the discussion in a way I think the PCAST, our committee - the faculty committee will need to do.

Paul Egerman – Software Entrepreneur
Carl that's extremely helpful. Picking up on Wes's comments, how do we get some of this information so that all the team members also have it, the workgroup team members? Wes suggested of the Q&A with the PCAST -

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… Crawford do a summary

Carl Gunter – University of Illinois – Professor
The link to the ULS report is in the slides here and the ULS report is very clearly written; however, it's directed to military applications and so I think it's much stronger on the articulation of the problems of a weakly regulated cyber infrastructure than it is on solutions that are appropriate to the U.S. healthcare system. I think it's very good for the kind of topics that were discussed at the meeting including looking at all the things they say and asking are these problems that we're going to have. That I think is better than a summary coming from the committee.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I suggest that we follow that link and we read the report.

Carl Gunter – University of Illinois – Professor
It's a very readable report even for skimming.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I think that the area where we can benefit most from a summary is the one that I heard Chuck specifically talk about, which is the summary of the presentations and the questions and answers by the principles of the PCAST report. Not to be advertising my own blog here, but I did find another description of the challenge of ultra-large systems that has more direct tie in to healthcare and I did put a URL to that on my blog yesterday or the day before.

Paul Egerman – Software Entrepreneur
That's great. Returning to the slide that Chuck put up here is there anything else that we want to ask of Chuck.

M
Yes, Chuck, one of the questions that I had asked a number of weeks ago in anticipation of this group meeting was relative to the computational requirements that would be associated with actually deploying the PCAST recommendations. I was curious if there were any discussions about what the computational implications might be if we did provide data at the atomic level, that was one and the other was about if

there were any discussion or debate about current architectures that might be used as an alternative to PCAST and if there were any conclusions relative to those discussions.

Chuck Friedman – ONC – Deputy National Coordinator
Those are important questions, we can look at them. I wasn't sitting in on all four groups so I don't know everything that was discussed and my memory of what was discussed on the first day is imperfect but we will bring those questions to the records we have about the meeting.

I just want to ask you about computational requirements. Are you talking about sheer cycles or are you talking about different kinds of requirements?

M
There was a section in the PCAST report that talked about what it would take to implement this at for instances in the EHR level, but in deploying the architectures that we're talking about there appear to be an understanding of a centralization of some of the - registry of sorts to be able to supply the services that were going to be required. In looking at that, were there any discussions about what that might look like as we began to really understand the full impact from an economic deployment perspective, number one, but also, obviously the reasonableness of being able to do this today and if there were any examples in other industries of ways to be able to do that. My concern really was around the overhead associated with the data package that was going to be anticipated with all of the information that was going to be gathered and if it was reasonable to deploy that within the architecture that was anticipated.

Chuck Friedman – ONC – Deputy National Coordinator
Thank you, I've got it.

M
Okay.

Steven Stack – St. Joseph Hospital East – Chair, ER Dept
If I could- I'm trying to do - three things that I think about, the first is much of what I hear in this recent discussion that we've just heard here is about the how to do it, the technology behind it, I'd say a lot of it as I hear it sounds when we get to privacy and security sounds more like security discussion instead of privacy so how the integrity of the system is preserved, how only appropriate access is permitted, even though I know privacy is discussed.

I have I think, two or three questions, one is for those of you who are the technology savvy individuals it sounds like there's not a lot of consensus on this yet which is why we are having these discussions, so what is the timeline for this? And I ask that in the context of we have a meaningful use program marching forward with progressively more robust exchange requirements for 2013 and 2015. It sound to me like science fiction at this point that we won't reach consensus, move forward, design this system, code it, and have it operational in the short of a four year timeframe.

The second thing is clarity on security versus privacy as we go forward, integrity versus what we're doing. Because, I think we've got some confusions from the end user level, from patients and clinicians that you may block out someone's HIV status, but if their medication list is complete and you anti-retroviral medications, it makes no difference that you blocked out the field that said they had HIV. On the other hand, if you also block out their full medication list, then the promise of med-to-med and med-to-allergy reconciliation that we're trying to advance is gutted for a substantial number of patients, same thing with mental health. I guess I'm lacking clarity a little bit on what the timeline people would envision any of this as responsible and how it interfaces with the efforts that are currently underway to advance meaningful use of a health IT adoptions. Some of that may not be germane specifically to this workgroup, but it is certainly germane to the overarching ONC charge.

Paul Egerman – Software Entrepreneur
Yes, and Steve those are excellent questions and in some sense I think a fair percentage of those questions, it's our responsibility as a workgroup, at least not necessarily the answer, but to at least sketch out what the alternatives are as to what might be done in stage two of meaningful use, what might be done in stage three of meaningful use and how the PCAST report impacts the current activities there that ONC is undergoing. It's sort of, the way I'm looking at it and I appreciate if Chuck or other people would correct me, I look at the PCAST report, I look at what Chuck just presented and it feels to me like this is like a computer scientist approach to information exchange and what we are going to be looking at is the intersection of that theory with the basic reality of what is on the ground right now in terms of what we're doing.

How do react to that, Chuck?

Chuck Friedman – ONC – Deputy National Coordinator
I think you said something very important that I probably should have said right at the beginning of my remarks that one of the purposes of the meeting that I reported to you today was to bring a primarily technical/computer science/information science perspective to this problem. We did that fully recognizing that is just a subset of the perspectives that ultimately must come to bear in order to get to where we need to go. To the extent that this report, this meeting, and what we call out of it for you is going to be helpful, it's going to be partial of course and one way in which it will be partial is that it does reflect the composition of the group that we intentionally brought together to create a more technical set of illuminations.

Paul Egerman – Software Entrepreneur
Basically, Chuck, what I perceive, I don't know if I got this right, but this is like a computer science technical vision of the future.

Chuck Friedman – ONC – Deputy National Coordinator
Well, but I think everybody in the room in creating that vision was aware that it was a partial vision.

Mark Rothstein – University of Louisville – Chair of Law and Medicine
There's at least one view point that I haven't heard expressed at all and that is of position groups. During the NCVHS's long hearings it was pretty consistently expressed by representatives of various medical colleges, that in specialty organizations and societies covering a whole range of medicine that patient directed granular controls were unacceptable from a clinical standpoint. I don't see that reflected here at all, and that is such a central part of what any system is going to come up with.

Paul Egerman – Software Entrepreneur
Good observation, Mark.

Chuck Friedman – ONC – Deputy National Coordinator
It illustrates what I believe was the sentiment I was trying to express before, that this is a partial view, it was multi-stakeholder, but not all stakeholders and it was skewed toward a particular set of stakeholders. Some viewpoints were simply not in the natural scheme of things going to come up here because representatives of those viewpoints who would articulate them were simply not there.

Paul Egerman – Software Entrepreneur
One question I had, I was interested in Wes's comment, when you used the word evidence, to what extent are you considering looking at the National Health System in the United Kingdom as possible evidence as to how these kinds of large scale systems might operate for healthcare?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Chuck, can I respond to that?

Chuck Friedman – ONC – Deputy National Coordinator
I assumed you were going to respond. No, Wes, I assumed you were going to respond.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I personally feel that there are some good accomplishments in healthcare interoperability associated with the connecting for health portion of the National Health System in England, but some spectacular failures in terms of health IT that go more to program management and program design. By this I mean, national programs not computer programs. It does make it necessary to do some interpretation of the results from HMS in order to learn the lessons. Currently the change of party in power is leading them towards a decentralized management approach that actually looks more like the United States Healthcare System. The potential that they can adapt what they had for what we've always thought of as an economic mess will be interesting.

In general, I think people look at what went over there and associate it with the problems with installing EHR's at a very high level as opposed to the interoperability issues.

William Stead – Vanderbilt – Chief Strategy and Information Officer
I have a slightly different view of the ultra-large scale system work. I actually think it's quite difficult to think about it as an information system only, and I think that's probably an inaccurate way to think about it, because if I understand it, what it basically is saying is that complicated systems which may be a provider organization, doesn't have to be the whole healthcare system, are socio-technical systems. You actually cannot meaningfully provide a part of that system, such as its information system or if you think of it as it's nervous system, across all of the entities that make up a complex, adaptive system. What you've actually got to do is to figure out how to provide infrastructure or whatever that works well at the boundaries of those systems and actually lets the internal part of those systems evolve and adapt as a socio-technical combination.

So I think it really is describing healthcare as we know it and other things that are equally complex. I agree with the statements that have been made that the report defines the problem and it provides directional alternatives again, much as PCAST does, it doesn't actually suggest solutions for either defense or healthcare at a detailed level. I think it's probably important to recognize that we'll be exploring the meaning of that, just like we're exploring the meaning of PCAST.

I really support the suggestions that Chuck, if he can, give us as complete a organization of the testimony and related Q&A around the key pieces people have mentioned, atomic data, timeline, somatic plug-ins, and sort of a number of moving parts or the computational challenges of the number of moving parts of all the coupled pieces.

Paul Egerman – Software Entrepreneur
That's excellent.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Paul, can I raise my hand one more time.

Paul Egerman – Software Entrepreneur
Yes

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Just wanted to comment that you can look at what we learn - first of all, it was wonderful to have the introduction to the ultra-large systems and Googling it afterwards I was amazed at how little - how specific the clusters are, it's got a lot of … defense I think and it's highly applicable. I would say that there are elements of the PCAST report that at least my school of poetry interpretation interprets as being quite resonate with that in the sense that it talks about establishing a specific infrastructure in the sense that it's specified, but it is deliberately focused on a few elements of all of the things that might be in a well-regulated IT infrastructure and relying on natural economic forces to fill in the gaps.

One area I would probably just want to modify what Carl said at least to make me happy, which is he described ultra-large systems an alternative between having an ultra-large system that was well regulated

or not. If I took anything from the presentation it's that the scale of ultra-large systems is such that the kind of detailed regulation we're use to in - at least inspiring to within our institution's, whether we achieve it or not is just inconceivable for system 12 or ladder systems.

Paul Egerman – Software Entrepreneur
That's an excellent comment. This will be the last comment, go ahead Carl.

Carl Gunter – University of Illinois – Professor
The thing that bothers me with the term, ultra-large system, is that what we're really talking about is whether the system is weakly regulated or not and actually the size is not the direct factor here. When the PCAST team gave their presentation they argued to some degree this system, the U.S. Healthcare System is by some standards, not large let alone ultra-large and that the question is what should be the extent of regulation on the system and choices of low-levels of regulations because the kinds of problems you see articulated in ULS report. Higher levels of regulation cause you problems in other directions and so that we both get to pick the degree of regulation and also the solutions to these problems depending on the place it's chosen.

Paul Egerman – Software Entrepreneur
Excellent comments and this has been an excellent discussion. Let me thank you very much Chuck for putting together this material and bringing us through this information. If you are able to get some of the material that we requested to us that would be extremely helpful. Even if we could get like a transcript of the Q&A session with the PCAST representatives that would also probably be helpful to us.

Chuck Friedman – ONC – Deputy National Coordinator
Yes, I think - I'm sure we can do that and I too enjoyed the discussion and thank you all very much. We'll get right to work on this.

Paul Egerman – Software Entrepreneur
Great and if you got to us by February 14th, which apparently is Valentine's Day, we will love you forever.

Chuck Friedman – ONC – Deputy National Coordinator
Thanks very much.

Paul Egerman – Software Entrepreneur
Thank you, the next thing that we wanted to talk about and it's a great discussion for the hearing, I think it's very important that we have a common view of what the PCAST report says, at least at a directional level. The information we got from Bill Press is that we should look at the PCAST report as a series of like directions. Bill Stead and I tried to put together this summary that we emailed and showed you before and what we wanted to do is to walk you through this and see if there's a consensus that this is a correct summary of the major directions of the PCAST report. There's really two pages to this, this is intended to be very high-level.

What you see is on the first page it says, there's three major directions and it's got a few things underlined. The first one says accelerate progress, the second direction is an exchange architecture, and the third thing that's underlined is evolutionary. Then there's a little bit more detail, the first sentence says accelerate progress, that phrase actually comes almost exactly from the executive summary that's in the beginning part of the PCAST report. The second major direction take a lot more words in it, underlines the concept of exchange architecture, it mentions the universal exchange language, supporting infrastructure and just simply says, strong privacy and security safeguards. Then, there is a sentence that says, the exchange architecture will enable physicians and patients to assemble a patient's data across organizational boundaries consistent with persistent patient privacy preferences. Try saying that five times fast, persistent patient privacy preferences. The third concept is an evolutionary transition that builds on existing EHR installations and HL7's clinical document architecture.

Let me pause there and see - to me this is very important the people - what's people reaction to this, people agree, disagree, is this close? What do people think?

Carl Gunter – University of Illinois – Professor
I had one comment. I thought it would be worth emphasizing a little more the two key functions one of them being the universal exchange language, the UEL, and the other one being the DEAS which is the search engine, these two functions are what are the key of the report, and the DEAS, I think does not receive the level of attention that maybe we should be paying to it. This doesn't even directly mention it.

Paul Egerman – Software Entrepreneur
Okay, and the next question is would you mention it as the DEAS or would you call it something a little bit more generic like a locator or a search capability or a - ?

Carl Gunter – University of Illinois – Professor
There are two functions here, there's a standardized data exchange language, and then there is an interlinked search mechanism.

Paul Egerman – Software Entrepreneur
Interlinked search mechanism.

Carl Gunter – University of Illinois – Professor
The search is determined by the metadata that's contained in the data; the relationship between the search and the data.

Paul Egerman – Software Entrepreneur
Okay.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Just building on what Paul said, I think most people regard those as two connected proposals that is without the notion of the universal element language the DEAS is not a sensible approach and the DEAS provides the value proposition associated with the universal element language. I'd like to suggest that item number three here is not incorrect, but it could be read differently by different people. It clearly is the evolutionary transition is intended to start with this being EHR installations and CDA and go somewhere else, it's not intended to imply that it's more of the same. It particularly criticizes the CDA for being document oriented and has other specific issues that it wants to see fixed during the evolution.

Paul Egerman – Software Entrepreneur
Those are good comments. Before we get on to your comment about number three, I want to make sure everybody's on agreement with Carl's statement, you seem to agree with West that we sort of like promote his concept to interlinked search that, that's like a major concept that we ought to be listing in the major directions. Is there anybody who disagrees with that?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I agree with that, but I would use exactly the terms that the report uses because the DEAS and the universal exchange language are two concepts that absolutely permeate the entire report and I think that we would be better served, our interests would be better served by using those terms themselves.

Paul Egerman – Software Entrepreneur
That's helpful.

William Stead – Vanderbilt – Chief Strategy and Information Officer
One of Paul's and my thoughts was that we need to get - it would help us if we could identify directional statements that were not technically prescriptive because one of our charges is to come up with the alternatives for achieving the directions. It might be helpful if we could have language such as Carl described that gets the key idea down, but doesn't run the risk of being viewed as technically prescriptive because then we're able to sit down and say okay, here are some alternatives one of which may in fact be - for each area one of those alternatives presumably would be what was identified as an example in PCAST. Bill Press was pretty clear that the specific technical suggestions were simply examples.

Paul Egerman – Software Entrepreneur
Those are good comments.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I don't think either of those terms is described as a technical -.

Paul Egerman – Software Entrepreneur
I think that - those are good comments - your comment is excellent Dixie, Bill's comment is excellent, at this point in the discussion I just want to make sure we understand the concepts. I'm not real worried about how we exactly word it. The main concept is to promote this interlinked search capability, whether or not we call it DEAS is sort of like a word … issue.

Carl Gunter – University of Illinois – Professor
I think it would be nice to reserve the terms in the PCAST report to the extent that they do suggest - In the PCAST report they do have fairly specific recommendations on how the DEAS and the UEL work and so we might want to hold those terms in reserve for solutions that do use those specific techniques and at the same time use more general terms like, data and search. I think those capabilities for more general discussion like discussions of alternatives, doing it differently say, from the way the DEAS does it.

Paul Egerman – Software Entrepreneur
Great comment. What I'm hearing though, I'm hearing a little bit of debate about how we word this, but I'm not hearing any debate about whether or not it's included in the bullet number two. Is that right? Another words I don't hear anybody say no, but don't include it, what I'm hearing is everybody saying exchange architecture so like the two interesting or novel concepts one is the universal exchange language and the other one is this interlinked search or DEAS that we need to mention them.

Based on that, unless somebody else - does anybody have any other comments about item number two before I go to Wes's comment about item three?

Okay, so Wes raised an issue about the third bullet here which is the evolutionary transition and we talked long enough - why don't I ask you West to state it again to make sure I get it right?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
You're challenging me to either remember what I've said more than this many seconds ago. My concern was that some people might read this as an implication that the authors of the PCAST report thought that existing EHR's and the CDA were - what they want to do is they just want to expand it a little bit and I think you have to read the report as saying that they recognize those that is where we are that they want something that is different and so to a certain extent it builds away from existing EHR installations and CDA and that's not a good choice of wording, but we're not trying to get the wording right here.

Paul Egerman – Software Entrepreneur
Other comments?

Tim Elwell – Misys Open Source Solutions – Vice President
I would concur with that. I think that's exactly right. I think that they were looking at an alternative to the existing, so an alternative wouldn't necessarily be stated as the evolutionary move.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
No, I think they were clearly recognizing that we aren't going to change the airplanes on this airplane while in the air unless we do one engine at a time. Evolution was clearly on their mind, it's just that it was not, I don't want to use the word that comes to mind, let's say it was directed evolution.

Paul Egerman – Software Entrepreneur
Not getting in to a response that counts as direct evolution. Actually, I think if you read the executive summary it does say, evolution. It does praise CDA, although it calls it ONCs critical document

architecture sort of stresses at the HL7 so apparently that's the correct designation. I think it does say evolution and then Bill Press and his presentation to us, he talked about evolution he expanded a little bit, he said evolution using middleware. I don't think he needed to say the middleware piece, I think it's an important concept … people think of the PCAST report means, throw away what you've already got.

M
There was a very directed question as I recall where we asked if the CDA architecture was looked at as an option. Why was that falling short of the recommendations for the PCAST report? He said that they didn't look at that carefully and they didn't think that was the correct architecture.

Carl Gunter – University of Illinois – Professor
In the report I think they list three specific criticisms of CDA and so one could interpret those things could be addressed incrementally than maybe evolutionary if they're affecting CDA so radically that you may not be able to do it in an evolutionary fashion. One could look to those three specific criticisms.

Paul Egerman – Software Entrepreneur
I guess my view is, I really saw the word evolutionary in the executive summary and I saw that in Bill Press's presentation and I also think we almost have no choice but to do it this way. The document says there's no rip and replace and so I think -

William Stead – Vanderbilt – Chief Strategy and Information Officer
I believe what they're talking about, I think Paul is absolutely correct that what our transition to any new model needs to be evolutionary and needs to not diminish the value of what we're doing now, but actually increase it. The way I read the report is we achieve an evolutionary course as a country in terms of healthcare IT by … a revolutionary approach to interoperability at scale, side by side with the approaches we have today. Use the approaches we have today, both locally and for certain types of, if you will, low-dimensionality interoperability while relieving those approaches of the stress, strain, and cost of the high-dimensionality, very complex information source interoperability that to date we haven't been able to figure out how to handle in the current approaches. I think there's an opportunity - I at least read it as a revolutionary approach sitting beside the current approach resulting together in an evolutionary transition. I don't know if that makes any sense.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I think that was very good. I might summarize it by saying it's a revolutionary approach in a revolutionary direction.

William Stead – Vanderbilt – Chief Strategy and Information Officer
Agree

Paul Egerman – Software Entrepreneur
Okay, my question is then are we okay with what's written here? Do we need to alter it in some way? For number three.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I just think as written it doesn't - well, I guess if you take it in the context of bullet two than its okay.

Paul Egerman – Software Entrepreneur
Yeah, because number three is evolution of transition, so evolutionary transition to what? It's what's ever in bullet two. In some sense you look at these things in sequence, together. You have accelerated progress, which means increase priority. You have exchange architecture, that's the revolution. Number three is you have evolution, we're saying, we are built on what we have; we're not going to do rip and replace. One and three might appear to have a little bit of stress between - creative tensions between the two of them, but it's also reality.

M
Any two of the three has tension between that should be true of all futuristic reports, right. I think if you were to change number two to say, establish a new exchanged architecture then it comes through more clearly.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I might suggest that we say in three that we established an evolutionary transition from the existing EHR installations to the desired future state.

Richard Platt – Harvard Medical School – Professor & Chair
May I ask a question about number two, I think the first sentence is fine, what's lacking in the second sentence is any specific mention of the need to address meaningful use and related population health measures because the architecture that supports one won't necessarily support the other?

Paul Egerman – Software Entrepreneur
You would make sure population health is mentioned in there. That's a good point because that is an emphasis that's in the report that really is at least so far is not been emphasized as much within ONC is described in the reports. That's a good comment. We'll include that in number two.

Turning to number three, it sounds like Dixie has a bit of a words missing, a suggestion. My question is are we okay with this combination as our three major directions? Accelerate progress, exchange architecture, and evolutionary.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I think we all, I guess I'll try to speak for everyone, I'm amenable to getting slapped down, I think we all agree that together as we have discussed and expressed the right thing, we're concerned that the wording as it stands might, can easily be misread in terms of the revolutionary nature of this. We have suggested to you a couple of different wording changes that might relieve that possibility and since you're going to do the wording we should leave it and see what you do.

Paul Egerman – Software Entrepreneur
Okay

Carl Gunter – University of Illinois – Professor
I wondered if we could put this off until after we hear the testimony of the PCAST people next week.

Paul Egerman – Software Entrepreneur
Well, we can - the issues we can and we can't. The reason why I say that is - I look at the schedule that we have the PCAST testimony on February 15th, then February 16th we have a three hour workgroup meeting and then we have two more conference calls, then we're done. To me what would be very important would be to have a common sense of the PCAST report going in to the hearing to help us structure what we're going to come up with in terms of our analysis.

Carl Gunter – University of Illinois – Professor
It's just so many of these questions could be resolved, just asking them.

Paul Egerman – Software Entrepreneur
Asking the PCAST people?

Carl Gunter – University of Illinois – Professor
Yeah.

Paul Egerman – Software Entrepreneur

Let's do it this way, great comment Carl. Let's do this, let's see if we can view this because everyone turn to the next slide, it's sort of like preliminary and then based on our interaction with them we can change it. Does that work for you Carl?

Carl Gunter – University of Illinois – Professor
That sounds like a good solution.

Paul Egerman – Software Entrepreneur
Based on what we know right now, and excellent comment because it very well be that they would look at this and say, oh yeah, that's exactly right or you guys are totally missing the boat and what I can do after this call is I can email it to them and ask if they have any comments on it too.

The next slide, here's what Bill and I tried to do is we tried to look at this concept of the exchange architecture and see if we could describe the fundamental concepts. Also, we did our best to describe them as high as we could in terms of not necessarily using the same wording as in the PCAST report, but just to describe them. You have a series of things here; the first one, the use of an extensible language; the second one, to pick up a PCAST wording, a more atomic approach to exchange; the third one made simply promoted us to the first page, we won't list it doubly here but the functionality to locate and aggregate data element; the fourth one is privacy safeguards that travel with the data; the next one, patient centrality, that was a reference to when you read the PCAST report they talk a lot about the EHR and patient access. Then you get to a little more technical stuff …, …, and semantics. We took the entire security discussion and just called it layered security. What are people's reaction to this, is this a good summary? Is this completely off track what you think?

M
On the security one part G one of the recommendations is separation of concerns, technically slightly different from layered security, although, probably there will also be layered security.

Paul Egerman – Software Entrepreneur
What should it say there instead of layered security, how would you phrase that?

M
I think they actually literally use the technical security terms, separation of concerns. The idea is that you have an IT entity, the DEAS doesn't handle medical data and the separate was the medical handling entities and separate inference.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I think in this first bullet the essential modifier to language is not extensible, it's mark-up because the PCAST report categorizes both as universal exchange language as well as the extensible mark-up language as extensible. I think we need to include the word mark-up there to indicate we're talking a tagging language, not a controlled vocabulary.

Paul Egerman – Software Entrepreneur
Okay. Let me ask this question is there something that you would call an architectural concept that's not on this sheet that should be here?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Paul, I'm having a little trouble with F. Can you help me understand what you mean by the semantics being plug-ins?

William Stead – Vanderbilt – Chief Strategy and Information Officer
Basically, that's a direct quote from Bill Press and it refers to that language I still find a little obtuse on page 70 of the report.

Paul Egerman – Software Entrepreneur
Yes, what I asked him about.

William Stead – Vanderbilt – Chief Strategy and Information Officer
In essence what I read it is this, we should continue to develop useful, controlled vocabularies and somatic knowledge sources, but we should view them as plug-ins to the universal exchange language. By that, I think it means that we would have a way of identifying which of those somatic standards was in fact used within whatever atomic data followed, so that it would not be a prescriptive language, if you will, but we would in fact be able to use any semantics that existed.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yeah, I think that's a great point. Well worth emphasizing at this level. In a summary, I would like to see what you just said accessible to people who read this slide though.

Paul Egerman – Software Entrepreneur
Is there a way to do that, can you make a suggestion, Wes?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I would say that decouple the syntax and semantics, anticipate rising levels of somatic spasticity in support and deal with variable levels of somatic spasticity and data.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I think what we've missed with regard to semantics here is if we could emphasize quite strongly in the report is the idea of mapping various vocabularies into this universal exchange language. I think we need to capture that as well.

Paul Egerman – Software Entrepreneur
That's helpful Dixie, but getting back to what West said, I think you described it real well. Your coupling syntax and semantics to provide an environment where there's varying levels of spasticity assigned to the data, but you've established a structure that can anticipate a right levels of somatic specifications, stuff like that.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
If you want to email me afterwards I can - I think we need to work the word rising in there somewhere, but fundamentally rather word … it on the phone, I'd be happy to talk to you about it off-line.

Paul Egerman – Software Entrepreneur
Great, terrific.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I think we still need to capture the idea of somatic mapping into the universal exchange language.

Paul Egerman – Software Entrepreneur
Well, instead of somatic mapping's, I'm wondering if you use the middleware in the evolutionary process, or do you want to do somatic mappings?

William Stead – Vanderbilt – Chief Strategy and Information Officer
I believe what they're saying we need to map, at the top of page 70, is the common identifier of the various somatic reference standards, if you will. They're not actually - I don't think they're actually suggesting that we map them all to one another, … I think they're simply saying they need to map how they fit in to the UEL and that could be as simple as providing a unique identifier for each of the standards in a place that exists in the UEL.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I'm amiss for not having the document open already here, but I had a sense and I'm trying to figure where it was in the report now that this is more of a lot - a lot of the references Bill were not as concrete as you

described and I almost kind of informal condensations categorize as the hail Mary pass the middle layer. I just want to be sure that if we take the specific citation that you have created and had it identified that it's representative of the entire report and not just that section. Again, I'd be happy to look at it off-line when I can find it and open it up and send you comments, but you guys decide what to do.

Paul Egerman – Software Entrepreneur
Why don't I ask you West and you Dixie to both look at that and send us your comments on it? My impression was similar to Bill's, although it may be because the both of us were very focused on that page 70 and then I had a discussion with Bill Press on it, he was apparently the author of that section. What he told me was exactly what Bill Stead just said, it was what they said on page 70 was they just want to have a syntax that will work for the range of things that we may do in terms of how the level of spasticity we decide and also he was very clear, at least on the phone, I interpreted his comments as, is all intent that this would interrupt any of the work that is currently going on to choose things that say, like use RX norm for medications or to use LOINC for laboratory data. This is not at all displacing it; it's just providing a structure to express it.

John
I would be happy to join Wes and Dixie in looking at that, because as I've talk to many of the folks too, I've had the sense of - at what point in data exchange does one bind the semantics to the data? That is might you actually not necessarily encode in a controlled vocabulary the data at the point of generation and as you say do it in middleware or even do it at a later stage after data is aggregated in the data atomic fashion. I think the wording on F, does need to be enhanced a bit to reflect all the ideas.

Paul Egerman – Software Entrepreneur
Okay.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I just have to - I don't know if this will affect our outcome on this point, but I just have to say that the notion that the coding system is independent of structure is not one that has stood up in actual on- the- ground creation of interfaces so far. We need to the extent we're making ultimately make recommendations on how to go forward, we have to keep that point in mind.

Paul Egerman – Software Entrepreneur
Okay, that's a good comment.

Gary Marchionini – University of North Carolina – Dean & Professor
Can I raise a question about the point E, the patient centrality?

Paul Egerman – Software Entrepreneur
Yes

Gary Marchionini – University of North Carolina – Dean & Professor
Because this speaks to the architecture and the exchange architecture, I guess I'm wondering does this point E suggest that the patient is the sort of atomic level that we're talking about in the architecture, so that would sort of suggest that a medication, a trial, any event would not be?

Paul Egerman – Software Entrepreneur
I'm not sure how to answer it, because first when you said patient atomic, I was like instinctively should know, no that's not right, but then the next part what you said sounded right. The concept the patient's centrality was sort of like in the midst of all this stuff that we're talking about, atoms and data elements is we're supposed to be focused on the patient and so there was in the various parts in the PCAST report there was a lot of discussion about the patient, PHR, patient' having access to their data, patient's being able to take their personal health record and exchange it in the sense of provide information to physicians. Those were the concepts that were referenced, at least in my mind.

Carl Gunter – University of Illinois – Professor

One problem we have here is a problem that looks a little bit like motherhood and apple pie that it should be patient centric. What one needs really is a little more elaboration of what a non-patient centric system would look like and what its virtues and trade-offs might be. I think it's intended to be a contrast with institution centric, but I'm not even sure that there' a definition of that out there one could say what that is. It's fine to put it in the list and they do say that, but it has a little bit of vagueness about what's meant.

Paul Egerman – Software Entrepreneur
Great comment, Carl, because what you did is you sort of put your finger on part of the real issues. Right now, the EHR system is sort of institution/provider centric and to the extent patient's have access it's sort of like you get a little bit of access towards a portal and so maybe this is not exactly the right wording. Maybe, somebody could suggest better wording, but I think the report does describe the system that's not institutions centric.

M
It certainly tries to empower patients in ways that the current maybe doesn't. I think more … work to come up with a list of alternatives and trade-offs that would tell you what this meant as compared to some other reasonable architecture you might have.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
We had a fairly explicit dialogue with Bill Press on a previous call and as I recall that we were really talking about the discussion of, is this notion of patients centric related to the somewhat nebulous concept of data ownership, is it related to the physical architecture of where data is persisted on behalf of the patient. One of the … around the report is what the meaning of patient centric in that regard is. There may be have been an intention to really talk about an architecture where the institutional systems relied on third party data sources that were common in patient centric for their operational data. If that in fact were the intent, or a thought in the making, it's an area that needs to be examined extremely carefully.

Paul Egerman – Software Entrepreneur
One observation I would make, those are good comments, Wes, but one observation I'd make is first we've got to figure out how to express this correctly. But, my observation is on this observation of patient centrality part of our job is to sort of explain what the PCAST report says and then also to explain what alternatives that ONC has to implement that. This is sort of like the subject headers of an outline, something that at some point we're going to provide.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes, Paul I agree, but if we're going to say what the report says about patient's centricity, we either have to say that the implications along the line I described was that they weren't considering those issues, or they chose not to make statements about those issues, or they meant to imply certain things and that's why it's important to sync this now.

Paul Egerman – Software Entrepreneur
What do you suggest we do for this, Wes?

Gary Marchionini – University of North Carolina – Dean & Professor
I'm sorry I raised it.

Paul Egerman – Software Entrepreneur
It's great that you raised it.

Gary Marchionini – University of North Carolina – Dean & Professor
I was a little concerned about it being as part of architecture that it could get interpreted as being script in defining architecture. The terms like accessibility or involvement, I think what we really want to get at in that it's not that the records get built around just patients, but that patient's are involved somehow in their data.

<u>Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst</u> would suggest that we - the point is well taken that was just made, but I would suggest that we put this on the agenda and specifically ask them about it at the hearing.

<u>Paul Egerman – Software Entrepreneur</u>
I'm happy with that.

<u>Richard Platt – Harvard Medical School – Professor & Chair</u>
Can I raise the question about whether we are interested in exploring the distinction between data and information? Frequently, what we care about is information about the patient and that's less detailed than the actual data that goes into providing the information. There's a privacy preserving aspect to the saying of we've exchanged required information, rather than necessarily always falling back to the data elements from which that information is constructed.

<u>Paul Egerman – Software Entrepreneur</u>
That's a great comment. Is that exchange architecture or is that just an issue you want to discuss with PCAST or among ourselves?

<u>Richard Platt – Harvard Medical School – Professor & Chair</u>
Well, it is an issue I'd like to discuss, the question is does it have implications for architecture? I don't know the answer to that. If you say this is something to take up when we meet, that's perfectly okay with me.

<u>Paul Egerman – Software Entrepreneur</u>
Okay, I think it's a great comment. I just wanted to go back to this patient centrality. The sense I have is right now I get a sense of almost we've got to take that off the list and have more discussions on that. We don't really have any consensus of to what we're supposed to be expressing there.

<u>Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst</u>
Also, I would leave it on the list and flag it as needing clarification.

<u>William Stead – Vanderbilt – Chief Strategy and Information Officer</u>
I favor the later because I believe we know something needs to be there, we just don't know what it is.

<u>Paul Egerman – Software Entrepreneur</u>
Should we call it patient involvement or leave centricity, centrality there?

<u>M</u>
Let's use their words.

<u>Paul Egerman – Software Entrepreneur</u>
Actually, centrality I don't think was their word. I think we got that one. If we're going to flag it, it probably doesn't matter what we call it. I'll put them both on.

<u>Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst</u>
I think using their word was helpful for flagged items. Do the Bill trick here and site the page number, that's really great in focusing the discussion.

<u>Paul Egerman – Software Entrepreneur</u>
Do you have any other comments about what you see on this slide? Okay, so there's a number of issues here, sorry, I get a sense that were not all together there yet on these issues, but that's probably appropriate at this stage and so it's good progress. Before we open ourselves to the public comments I'm just going to quickly walk through what's going to be happening next.

First of all, everybody should have gotten an invitation for this optional discussion tomorrow at 11 o'clock. … is going to help people who are not familiar with ONC just to know what the ONC program's are. Here

is the stakeholder hearing agenda for Tuesday and basically we have an interesting challenge as we look at Tuesday's hearing which is really a filled agenda. The challenge is going to be to make sure that we keep the discussion on topic because there's so many issues that are here that are so very interesting that it would be very easy to go off topic. The challenge is to keep it on topic and the challenge is to think about - make sure that we keep the PCAST report itself in mind in terms of what we're doing that on the next day again on the 16th, Wednesday February 16th what we will be trying to do is actually start our deliberations. We're going to start by trying to see if we have a consensus on what we heard on the previous day. We're going to obviously start with discussing what we learned, but then if we have time start moving from there to some understanding of how we're going to structure our comments and how we're going to report out what other alternatives we're going to provide to ONC.

Let me stop there and see if people have any questions or comments.

Do you have anything that you want to say, Bill?

William Stead – Vanderbilt – Chief Strategy and Information Officer
No

Paul Egerman – Software Entrepreneur
This is going to be an exciting hearing and I'm very much looking forward to it.

Judy can we open the line for public comment.

Judy Sparrow – Office of the National Coordinator – Executive Director
Operator can you please check with the public and see if anybody wishes to make a comment.

Operator
Yes, if you are on the phone and would like to make a public comment please press star one at this time. If you are listening via your computer speakers you may dial 1-877-705-2976 and press start one to place into the comment queue.

Judy Sparrow – Office of the National Coordinator – Executive Director
Workgroup members, I've sent you about half a dozen of the testimony's to date so I'll send hopefully more tomorrow and just keep an eye on your emails for over the weekend testimonies any come in real late.

Operator
We do not have comments at this time.

Judy Sparrow – Office of the National Coordinator – Executive Director
Thank you operator.

Paul Egerman – Software Entrepreneur
Thank you and let me also once again thank the ONC staff, Judy Sparrow and Jody Daniel and if … was able to join the call and I'd say thank you very much and looking forward to our hearing on Tuesday. Take care.

Judy Sparrow – Office of the National Coordinator – Executive Director
Thank you.

Public Comment Received During the Meeting

1. The 3 major directions slide is misleading to our reading, we read PCAST to suggest a transition FROM traditional electronic health records rather than suggesting a transition that builds upon existing EHR. This seems to be a critical distinction. Could not contain myself. Thank you. I feel better now.

2. Patient directed control of what is shared is really what happens now as the patient is usually the conduit between different providers.

3. PCAST recommends that tagging would be done as part of physician workflows.

4. PCAST mentions the goal of HIE among a continuum of care settings that engages patients.

5. Specifically, PCAST recommends accelerating HIE and fostering HIT infrastructure

6. PCAST also says something about schedule...that these recommendations be incorporated into Stage II Guidelines for Meaningful Use

7. But HIEs, by HITECH requirement includes PHR component requirement

8. I haven't gotten the impression from comments that I have read that "evolutionary" is the interpretation.

9. They also said that the focus of ONC should be on exchange of information, as opposed to EHR implementation.